

Accelerating the Translation of MS Research into Practice with People-Powered Research Dissemination

Stephanie Buxhoeveden, PhD, MSN, FNP-BC, MSCN¹, Robert N. McBurney, PhD², Hollie Schmidt, MS³, Sara Loud, MSEE, MBA³, Laura Kolaczowski, BA⁴, Surachat Ngorsuraches, Ph.D.⁵, Seth Morgan, MD, Cassie Martin, BA⁶, Sara Bernstein, BA⁷ and Sherilyn George-Clinton, BA

(1)Accelerated Cure Project for Multiple Sclerosis (ACP) (2)Optimal Healthcare Outcomes LLC (3) ACP , (4) ACP, (5) Auburn University (6) Banner Health (7)National MS Society

Category	People-Powered Dissemination	Traditional Dissemination
Stakeholder Involvement	Patients, caregivers, clinicians, and researchers co-create content	Researchers lead, others are passive recipients
Accessibility	Tailored to diverse audiences (plain language, visuals, audio)	Dense, technical formats (journals, slides)
Formats Used	Multi-media (podcasts, infographics, webinars, summaries)	Primarily text-based articles and conference talks
Feedback & Iteration	Real-time input shapes dissemination strategy	Feedback is indirect, post-publication
Real-World Relevance	Designed for practical use in daily life and care decisions	Often abstract, slower to influence practice
Inclusivity	Prioritizes diverse, lived experiences	Focused on scientific or expert audiences
Translation Speed	Accelerates use of research through accessible content	Translation to practice can take years

Introduction

iConquerMS, a People-Powered Research Network managed by the Accelerated Cure Project for MS, brings together people with MS, caregivers, healthcare providers, and researchers in a collaborative model that centers the needs of the MS community. By engaging diverse voices, especially from underrepresented populations, and leveraging its robust engagement infrastructure, iConquerMS launched a dissemination capacity-building project to develop accessible, relevant, and actionable strategies for sharing MS research. Initially focused on PCORI-funded studies, these strategies are broadly applicable across multiple types of research and funding sources to ensure real-world impact on care and outcomes.

Methods and Materials

We used a stakeholder-engaged approach to co-create a research dissemination strategy tailored to the MS community. A 13-member multi-stakeholder Steering Committee guided all phases of the project. We conducted a landscape review, interviewed PCORI-funded study teams, and surveyed over 300 MS stakeholders to assess dissemination preferences. These insights informed the development of a multi-media dissemination plan, which was piloted using one PCORI study on a newly designed iConquerMS website. Focus groups and surveys with new stakeholders validated the clarity and usability of the final approach.

Results

- Created a **multi-media dissemination plan** responsive to stakeholder needs and format preferences.
- **Developed guiding principles:**
 - Audience-centered design
 - Accessible language/visuals
 - Diverse learning formats
 - Clear practical relevance
- Developed a **Dissemination Toolkit** and **new web resources** to support widespread adoption.

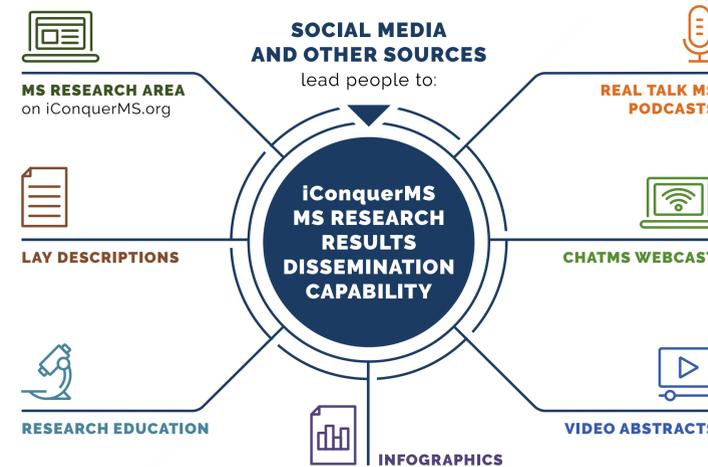


Figure 1. Preferred Dissemination Tactics by Stakeholder group.

Discussion

Traditional dissemination excludes many MS stakeholders due to format and technical language. The iConquerMS model:

- Centers patients and caregivers in **every stage of dissemination**
- Leverages digital tools for **greater accessibility and reach**
- Enables **faster translation** of research into practice
- Creates a feedback loop to inform **future research and communication strategies**

Conclusions

The iConquerMS DCB project demonstrates that **people-powered dissemination accelerates impact** by:

- Prioritizing accessibility and inclusion
- Adapting formats to meet audience needs
- Building trust and ownership in research

Next Steps

- Disseminate additional MS research using these tools
- Expand non-digital dissemination formats
- Include more diverse stakeholder voices, including payers
- Continuously evaluate and refine the strategy

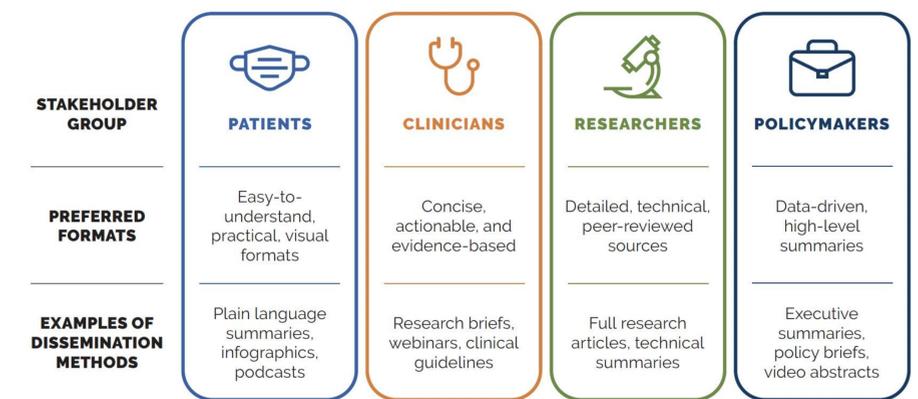


Figure 2. Preferred Dissemination Tactics by Stakeholder group.



References

1. Ayegebusi D.L., et al. (2023). Considerations for patient and public involvement and engagement in health research. *Nature Medicine*, 29(8):1922-1929.
2. The Multiple Sclerosis International Federation. (2020). *Atlas of MS*, 3rd Edition.
3. Harrington, R., et al. (2020). Defining patient engagement in research: Results of a systematic review and analysis: Report of the ISPOR patient-centered special interest group. *Value in Health*, 23(6), 677-688.
4. Heckert, A. et al (2020). Researchers, patients, and other stakeholders' perspectives on challenges to and strategies for engagement. *Research Involvement and Engagement*, 6(60).
5. Jakimovski, D. (2024). Multiple sclerosis. *Lancet*, 403(10423), 185-202.
6. Maurer, M.E., et al. (2024). Researcher and partner perspectives on the relationship between engagement in research and three uses of patient-centered comparative clinical effectiveness research study findings. *Research Involvement and Engagement*, 10(1), 105.
7. Morris, Z.S., Wooding, S., & Grant, J. (2011). The answer is 37 years, what is the question: Understanding time lags in translational research. *Journal of the Royal Society of Medicine*, 104(12), 510-520.
8. Stoll, S., et al. (2024). Insights for healthcare providers on shared decision-making in multiple sclerosis: A narrative review. *Neurology and Therapy*, 13(1), 21-37.